

COVID-19: social isolation and consequences in the lives of children with autistic spectrum disorder

COVID-19: isolamento social e suas consequências na vida de crianças com transtorno do espectro autista

COVID-19: el aislamiento social y sus consecuencias en la vida de los niños con trastorno del espectro autista

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ABSTRACT

Objective: to know the guidelines of health professionals about the consequences of social isolation, caused by the COVID-19 pandemic, on the development and lives of children with Autistic Spectrum Disorder. **Method:** field study, exploratory, descriptive and with a qualitative approach, supported by the references of Family-Centered Care and Bardin's Content Analysis and approved by the Research Ethics Committee. Developed in municipalities in the interior of São Paulo, from September to October/2021, with the participation of twelve health professionals. **Results:** the experiences learned followed instructions in the thematic categories: "Interruption of therapies and professional strategies", "Implications of the pandemic on the development of the autistic child" and "Social isolation of the pandemic and the family dynamics of the child with autism". **Conclusion:** the social isolation resulting from the coronavirus pandemic interfered in the lives of autistic children and their families, with consequences for social, motor, linguistic and pedagogical development.

Descriptors: COVID-19; Social Isolation; Child; Autism Spectrum Disorder; Withholding Treatment.

RESUMO

Objetivo: conhecer as percepções de profissionais de saúde acerca das consequências do isolamento social, causado pela pandemia da COVID-19, no desenvolvimento e na vida de crianças com Transtorno do Espectro Autista. **Método:** estudo exploratório, descritivo e de abordagem qualitativa, apoiado nos referenciais do Cuidado Centrado na Família e da Análise de Conteúdo de Bardin e aprovado pelo Comitê de Ética em Pesquisa. Desenvolvido em municípios do interior paulista, de setembro a outubro/2021, com participação de doze profissionais de saúde. **Resultados:** as experiências apreendidas estiveram representadas nas categorias temáticas: "Interrupção das terapêuticas e estratégias profissionais", "Implicações da pandemia no desenvolvimento da criança autista" e "Isolamento social da pandemia e a dinâmica familiar da criança com autismo". **Conclusão:** o isolamento social decorrente da pandemia do coronavírus interferiu na vida das crianças autistas e suas famílias, com consequências ao desenvolvimento social, motor, linguístico e pedagógico.

Descritores: COVID-19; Isolamento Social; Criança; Transtorno do Espectro Autista; Suspensão de Tratamento.

RESUMEN

Objetivo: conocer las percepciones de los profesionales de la salud en cuanto a las consecuencias del aislamiento social, provocado por la pandemia de la COVID-19, en el desarrollo y la vida de los niños con Trastorno del Espectro Autista. **Método:** estudio exploratorio, descriptivo y con enfoque cualitativo, apoyado en los referenciales del Cuidado Centrado en la Familia y el Análisis de Contenido de Bardin y aprobado por el Comité de Ética en Investigación. El estudio tuvo lugar en municipios del interior de São Paulo, de septiembre a octubre/2021, contando con la participación de doce profesionales de la salud. **Resultados:** las experiencias aprendidas se representaron por las categorías temáticas: "Interrupción de terapias y estrategias profesionales", "Implicaciones de la pandemia en el desarrollo del niño autista" y "Aislamiento social de la pandemia y la dinámica familiar del niño con autismo". **Conclusión:** el aislamiento social resultante de la pandemia del coronavirus interfirió en la vida de los niños autistas y sus familias, con consecuencias para el desarrollo social, motor, lingüístico y pedagógico.

Descriptores: COVID-19; Aislamiento Social; Niño; Trastorno del Espectro Autista; Privación de Tratamiento.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder, usually characterized by difficulties in social interactions and communication, with incidence of repetitive behaviors¹. The ASD diagnosis includes Autism and Childhood Disintegrative Disorder, as well as the Asperger and Rett syndromes². Regarding the cause of this condition, its origin has not yet been well defined³.

The global incidence of ASD is estimated at one in every 160 children⁴. In Brazil, the incidence is one in every 360 individuals, with an estimate that two million Brazilians are autistic, which represents nearly 1.0% of the population⁵.

According to Law No. 12.764, people with ASD are considered individuals with a disability, which guarantees them the right to early diagnosis and treatment with a multidisciplinary team⁶.

The ASD diagnosis is made through observation, and the first signs can be identified from the first years of life. Some of them include difficulty interacting with other people, speech delay and lack of visual communication⁷. Therefore, reports by parents and family members become extremely important and a distinctive factor for early diagnosis and initiation of the therapeutic plan^{3,8}.

It is a fact that both families and children with ASD struggle due to the difficulties they face on a daily basis. Acceptance by parents, the level of their condition, prejudice by society and, oftentimes, even the family's financial condition interfere in these children's life⁹. Health professionals stand out in this context, being responsible for devising strategies to fight against various possible scenarios¹⁰.

Furthermore, the multiprofessional team provides support to families and children with ASD and may consist of a psychiatrist and/or neurologist and/or pediatrician, psychologist, speech therapist and, sometimes, physiotherapists, educational psychologists and occupational therapists. These professionals work together to meet the children's demands, understanding their relationships and constraints while always respecting their particularities^{11,12}.

The World Health Organization (WHO) declared COVID-19 a global pandemic on March 11th, 2020, which required restrictive social isolation measures to contain spread of the virus^{13,14}. Faced with this scenario, the work of health professionals who provided care to children diagnosed with ASD was directly affected, thus interfering with their treatment and causing setbacks in their entire therapeutic evolution. The family context also suffered a disruption in its dynamics and functioning processes and, therefore, the need to stay at home broke family and therapeutic routines, thus intensifying moments of distress, stress and anxiety¹⁵.

It is known that, when it comes to caring for children with ASD, family organization focused on a well-planned and directive daily routine is an important strategy in the therapeutic plan. However, during the pandemic, several activities were interrupted, relationships with school environments and therapeutic spaces were disrupted, and interactions with family members were intensified¹⁵. Faced with this problem, the guiding question of this research arises: How did the social isolation caused by the pandemic context affect the therapy progress of children with ASD, considering their development and life?

Therefore, this study aimed at understanding health professionals' perceptions regarding the consequences of the social isolation caused by the COVID-19 pandemic on the development and lives of children with autism spectrum disorder.

METHOD

This is a descriptive and exploratory study with a qualitative approach that sought direct contact with participants who experienced the phenomenon under study, with acknowledgment of the subjectivity, symbolic aspect and intersubjectivity of the relationships and events experienced¹⁶. The Family-Centered Care Model was used as a theoretical concept and Bardin's Content Analysis as methodological framework.

Family-Centered Care strengthens family functioning once it understands how its intervening conditions impact the care of children with ASD. Thus, it is assumed that parents and other family members want to be involved in their care to obtain the necessary information and provide adequate health care¹⁷.

In turn, Bardin's Content Analysis allows learning about the life baggage and experience that come from caring for children with ASD, and it is understood as a set of communication analysis techniques focused on obtaining systematic and objective procedures for describing the content of messages, thus enabling knowledge inferences¹⁸.

The project was carried out along with health professionals who work in the care of children with ASD in three municipalities from the Mideast region of the inland of the state of São Paulo, namely: São Carlos, Brotas and Itirapina. These three cities together have a total of 260,054 inhabitants¹⁹⁻²¹.

The invitation to participate in the study was made using the Snowball sampling method, a non-probability sampling modality in which the researcher initially determines the characteristics of the sample, then identifies the group of potential participants and, after each data collection instance, those who were researched are requested to nominate new participants from the target population²². Twelve health professionals who were part of a multiprofessional team that worked in the care of children with ASD agreed to participate in the study.

The participants were contacted via telephone; they were previously informed about the research purposes, and subsequently confirmed their consent by signing the Free and Informed Consent Form (FICF). The inclusion criteria were the following: working directly in the care of children with ASD (considering "children" as the age group from zero to 12 years old) and having at least two years of experience in the care of children with ASD. In turn, the exclusion criteria used in the study referred to participants who were unable to provide an intelligible narrative.

The strategy used for data collection was semi-structured interviews, carried out in digital format on dates and times previously agreed upon via the *Google Meet*® platform. Initially, the following guiding questions would be asked: *Can you tell me how the therapeutic processes for children with ASD were approached during the pandemic? What interferences were detected?* and, based on these questions, others were raised, seeking to encompass the objectives proposed.

Data collection was carried out between September and October 2021 in a single one-on-one meeting, and the audio was recorded and later transcribed in full, totaling 163 minutes of recording. Readings and re-readings of the material were carried out until reaching theoretical saturation, at which point the study object was understood and the data collected began to be repetitive²³.

The Bardin's Content Analysis method was selected to analyze the data, which aimed at describing all the data from the interviews through a thematic indicator, focusing on the perceptions expressed about social objects and phenomena associated with them²⁴.

The study was approved by the Committee of Ethics in Research with Human Beings, following all ethical precepts established by the National Health Council²⁵. Furthermore, the participants had their identity preserved, being identified by the letter "P" referring to 'Professional' and followed by an Arabic numeral indicating the order of their participation in the study.

RESULTS

This study covered the experience of 12 health professionals, all women, residents in the municipalities of Brotas, Itirapina and São Carlos. In terms of their professional training, there were three occupational therapists, three educational psychologists, three physiotherapists, two speech therapists and one psychologist. Regarding their training experience, it ranged from two to twenty-four years, and their time working in the care of children with ASD varied from two to seven years.

The experience grasped regarding the COVID-19 pandemic implications on the development and life of children with ASD from the health professionals' perception was represented by the following thematic categories: *Treatment discontinuation and professional strategies*; *Implications of the pandemic on the development of autistic children*; and *Social isolation in the pandemic and the family dynamics of children with autism*.

Treatment discontinuation and professional strategies

As restrictions to human mobility were enforced to prevent coronavirus contamination, many institutions and professionals who worked in the treatment of children with ASD had to interrupt in-person medical care, which caused a sudden suspension in these patients' routines and led to several problems: they experienced setbacks in their treatment and development and a decline in their family relationships.

Not only were the children left without care, but there was also a break in their routine. I could say that this caused them harms also in terms of their social life. (P7)

The pandemic was harmful because people with autism have their structured routine, and if it's not duly followed, they get out of balance. (P5)

Even with the relaxation of social isolation restrictions and the resumption of rehabilitation services, many parents and guardians were afraid to get back to in-person treatment. Faced with this fact and seeking to preserve the bond with their patients, several professionals tried to reconnect with them and continue with the treatment proposed using digital tools.

It was suggested that we held face-to-face meetings, but it just wasn't possible the way we wanted because the mothers were too scared of attending these appointments, leaving their homes and running the risk of becoming infected and taking the virus into their homes. (P11)

When the pandemic started, this mother chose not to bring her son to the appointments anymore, but it was agreed that I'd treat him remotely, to preserve the bond. (P9)

I'd make booklets and record videos and send them to their parents/guardians, so that they could learn how to properly perform the exercises. (P10)

Remote care proved to be essential during this period of time, but it did not have the expected reach, either due to the children's age group or because they lacked access to technological devices or the necessary skills to use digital media. Another obstacle pointed out by some professionals referred to the children's difficulty following the treatment since agitation and inattention are behaviors usually associated with ASD, thus making it hard for them to remain focused on long-lasting interactive screen activities.

At the beginning of the pandemic, many parents wanted to withdraw treatment from their children. And, in most of these cases, it was not possible to provide remote care due to the children's reality and age. There were some who barely knew how to use a computer. (P1)

We had to think about new proposals for remote teaching, remote care, which ends up hindering knowledge incorporation. Therefore, many children were left without care. (P8)

Implications of the pandemic on the development of autistic children

Treatment discontinuation in children with ASD due to the pandemic affected their motor, social, pedagogical and behavioral development. Reports from the professionals mainly pointed to a decline in their social skills due to the absence of interaction spaces. Children who were able to interact socially regressed and, consequently, showed isolation behaviors.

Children who had been calmly walking to the room with us for a year would freeze in the waiting room and not want to enter. So, from the waiting room, we could already see a setback. (P9)

[...] most children isolated themselves from social contact in the sense of not wanting to share things, reach for other people or communicate with others. (P6)

The behavioral aspect was one of the most affected by this break in the routine, with emphasis on symptoms such as restlessness, aggression and stubbornness, reported as excessive “tantrums” by some professionals.

The patients returned totally messed up. I noticed that they were a lot more stressed out. Some showed temper 'tantrums', others would cry and be clingy to their parents because they were spending 100% of the time with them. (P6)

Regarding motor development related to physical mobility and language, the implications mainly inferred in children under the age of ten. Those who were showing speech, writing and self-care development regressed drastically.

The children's speech and writing skills showed certain deficit due to the fact they would stay at home with no therapeutic scope. (P4)

All of this resulted in setbacks and difficulties in terms of language, communication and social context. Children who were already feeding themselves, dressing themselves and communicating well, as they returned [to treatment], they no longer knew how to put on their shoes, struggled to brush their teeth, and had poor nutrition. (P3)

While staying at home, he wouldn't do any type of activity. So, when treatment was reinitiated, I applied a scale through which I noticed that his motor skills had declined. (P10)

According to the professionals interviewed, these developmental setbacks were related to excessive screen use during the social isolation period, a strategy resorted to by the families as a form of entertainment.

They showed a huge setback. At least my patients are struggling to manage their screen time. It's been very difficult, because as soon as they arrive, they're already using their mobile phones. (P4)

Another aspect that greatly damaged their development was the electronic device issue. Why? What did the parents do? They left their children use their mobile and tablet devices all the time. (P12)

Another potential space for social interaction that had its activities interrupted was the school, which plays an important role in the learning process of children with ASD. The absence of this environment contributed to a developmental setback in these children.

At school children learn to share, wait and take their time. But the absence of the school environment ends up being reflected on their behavior. (P2)

Social isolation in the pandemic and the family dynamics of children with autism

The fact of living together intensely on a daily basis during the social isolation period exerted a direct impact on family relationships. As parents were forced to be with their children all the time, many ended up finding themselves in stressful situations, mainly for not being able to count on professional care. In this scenario, family organization and functioning had to be restructured. Some of the professionals interviewed referred to conflicting relationships, especially between siblings.

We noticed that the impact was mostly on the family. So, families had to be restructured, but family members got desperate, some even lost their jobs. (P12)

When they started to live together, conflicts increased. And even one of the siblings is being currently monitored because he doesn't accept it. When they didn't spend much time together, everything was fine, but when they were forced to be together all the time, he didn't accept it and wanted to go live with his grandmother. (P5)

It was possible to understand that the families were not prepared to provide full-time care for their children with ASD in that situation, that is, without therapeutic support and away from the school environment. The limited applicability of the Family-Centered Care model in elaboration of the treatment plan justified these difficulties since, as the family was not included and actively engaged in the care planning, the family members lacked the necessary

knowledge and skills to do so. On the other hand, there are reports from professionals who monitored families and noticed the fact that many parents began to better understand their children and their needs.

In this social isolation moment, I instructed them to do several family dynamics. Faced with these dynamics, there were parents who thought their children wouldn't be capable of doing them, but they changed their minds. (P1)
[...] what I see as a positive factor about social isolation is that it helped many parents understand their children's particularities and see their small developments. (P3)

Another aspect pointed out by the professionals is that the families had difficulties interacting with the children, especially in defining coexistence limits and rules. As a result, there was an increasing emotional burden on the parents. Furthermore, many found themselves frustrated by the prospect that their children were regressing.

First, we had to take care of the family, because the family's signs of dysfunctionality and desperation about the situation were being reflected on the children and hindering their development. (P11)

The demand for psychological treatment increased significantly during this period, even for parents. They found themselves very frustrated at the prospect that their children were regressing. (P7)

DISCUSSION

Based on the perceptions of the health professionals interviewed, it was possible to understand the effects of social isolation on the development and lives of children with ASD during the COVID-19 pandemic. Treatment discontinuation combined with the break in routine stood out as the main causes exerting impacts on the development of these children.

In this sense, the interruption of activities in all social spaces and the intensification of family relationships had a drastic impact on children's behavior and development. The literature points to a significant increase in the fear, depression, aggression, hyperactivity, repetitive behavior and anxiety levels during the coronavirus pandemic^{26,27}.

Due to the need for social isolation, for a certain period of time it was inevitable that daily activities would come to a complete standstill, and every social interaction had to be suspended: children had nothing but the family environment in their daily lives, which consequently undermined all motor and social skills built upon by the professionals. This change in everyday life proved to be the main cause for the setbacks in social, motor, behavioral and pedagogical development²⁸, as reported by the professionals interviewed.

As previously stated, the stay-at-home period during the coronavirus pandemic was experienced with difficulty by children with ASD, as sudden changes in their daily routine cannot be easily adjusted, not to mention the challenge of not receiving any type of treatment. Associated with this, children with ASD showed irregular sleep patterns, as they were less physically active, lacked enough personal space at their homes and had longer screen time use²⁹, factors that were also highlighted by the interviewees in this study and seen as limiting for motor and social development.

Among the daily activities mentioned, the school environment, as we learned, is a strong ally in the development of autistic children. With the COVID-19 pandemic, schools tried to maintain educational processes using a digital educational system. However, as pointed out in the literature, such institutions have not shown efficient strategies to meet the needs of individuals with autism and their families^{26,29}.

In relation to social interaction, all interviewees reported a major decline in the children's progress, which not only implies verbal but also non-verbal communication. Moving further in this direction, some studies point to atypical behaviors in children when they returned to in-person activities; their struggle with self-control was evidenced, as well as their irritability and anxiety followed by agitation and aggression, both towards the professionals and themselves²⁹.

For a greater contribution to face the negative implications of the pandemic lockdown, there was a need to employ online therapeutic resources and services in order to minimize the impact on their future development³⁰. Thus, health professionals used strategies to maintain their interactions with children and minimize negative implications on their development. Therefore, remote assistance became essential, whether through video calls, phone calls, educational videos or booklets, with the objective of assisting family members by responding to their inquiries through group chat apps.

Despite all the efforts made by the participating professionals to continue the treatments, they reported that the children showed significant difficulties concentrating and being interested in carrying them out, as they were in their home environment, a demotivating factor. These results are in line with the findings of another study³¹.

Another important point analyzed were family interactions involving parents, siblings and grandparents who, at times, were unaware of the autistic children's behaviors and limitations given the limited time spent together before the pandemic. On the other hand, positive aspects were also observed as a result of intensified family relationships, as some parents/guardians were unaware of the complexity inherent to autism and ended up being surprised by the children's capabilities³². Therefore, the

pandemic period, in a whole context, was useful to bring some family members and guardians closer to the children, but there were also cases of intra-family conflicts reported by the professionals interviewed, which resulted in psychological harms to these families³².

Finally, it was observed that lack of knowledge about ASD was a challenge to be overcome by the families during the pandemic period, and that the absence of technical support from the multidisciplinary team made this challenge even more intense. The fact that autistic children had to constantly live with their families during lockdown turned into a very stressful situation for them, directly interfering in their behavior and leading to an emotional burden on parents and children; consequently, family members have been showing higher anxiety and depression levels^{27,33,34}.

Study limitations

As a limiting factor, the difficulty recruiting participants stands out given the COVID-19 pandemic context, in which social isolation determinants interfered with the participation process: the strategy chosen was online interviews and they were not familiar with digital media. Furthermore, the absence of nurses in the multidisciplinary team was noted, professionals whose role is unique when it comes to health care education both for children and for their families.

The study focused on Autism Spectrum Disorder during the pandemic has repercussions in disseminating the knowledge obtained to demystify misconceptions about these patients, so that we can all live in a society that is increasingly less prejudiced, more fair, egalitarian and respectful. Furthermore, it raises the issue regarding the need for Nursing professionals to actively work in multidisciplinary teams that provide care for children with ASD.

CONCLUSION

Based on the reports by the health professionals, it can be noted that the social isolation caused by the COVID-19 pandemic exerted a major impact on the development and lives of children with ASD, and a setback was observed in all areas investigated in this study, further impairing their abilities to overcome obstacles that have been previously worked on by the professionals.

It was no different for family life: there was indeed greater family closeness but some conflicts arose, evidencing gaps in knowledge that had never been filled and, in some cases, taking family members out of their comfort zone, thus bringing them into the reality experienced every day by children and professionals. On the other hand, this period served to raise awareness among family members and guardians about the complexity inherent to ASD and its particularities.

Finally, it is expected that this research can contribute, in academic and clinical circles, to further studies and analyses of the complications suffered by autistic children and their families due to the pandemic context.

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